Measuring Family Quality of Life for Children with Autism

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Introduction

Family Quality of Life

As defined by the World Health Organization, Quality of Life (QoL) includes a "person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment" (World Health Organization, 1997, p. 1). By definition, QoL could be applied to many aspects of a person's life from financial well-being to educational opportunities, and includes negative as well as positive features (Centers for Disease Control [CDC], 2011). Often, QoL is used as a marker in intervention studies measuring associated gains or losses especially as they relate to health-related challenges (e.g., Boylan, Flint, Labovitz, Jackson, Starner, & Devinsky, 2004).

Beyond the individual, researchers can also investigate family quality of life (FQOL). One way of doing so is by utilizing a family systems perspective (Minuchin, 1974). This perspective recognizes the important role each family member plays. Studying FQOL through family systems theory, also investigates how each family member influences the overall FQOL. Similar to QoL, FQOL could also be an outcome measure for family interventions (Summers et al., 2007).

Family Leisure and Satisfaction as Measures of FQOL

Agate et al. found that "when examining variables of religiosity, gender, education, marital status, age, and leisure satisfaction, leisure satisfaction was the only significant and direct predictor of quality of life" (2009, pp. 215-218). Their study was the first to state that this is true for families as well as individuals, emphasizing the importance of family leisure satisfaction. In addition, Zabriskie and McCormick (2003) found that family leisure was often planned by parents to improve family functioning and family satisfaction. With family leisure playing such

an important role in family satisfaction, family leisure appears to be a logical choice when measuring FQOL.

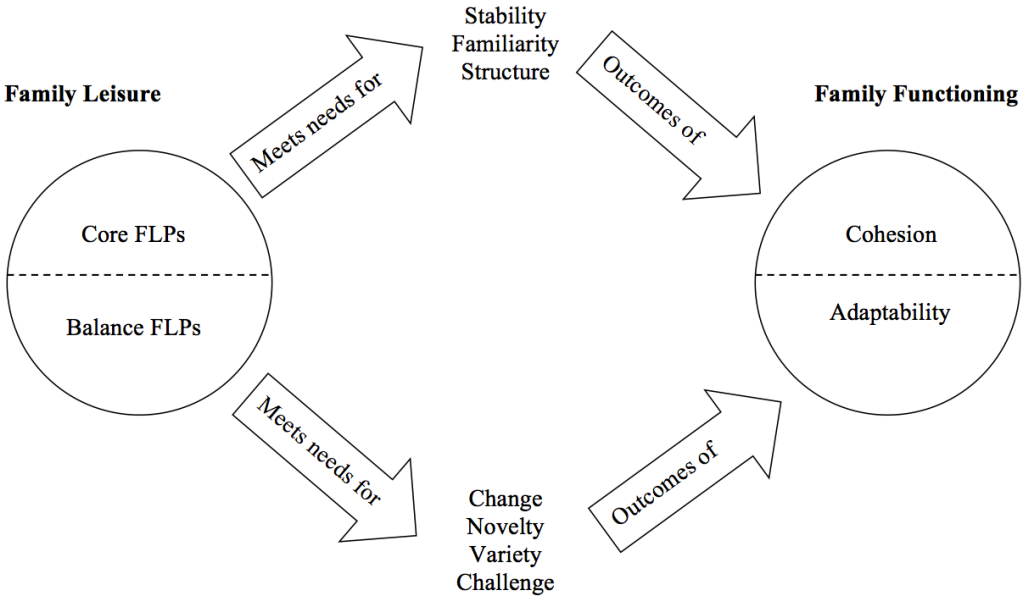

Figure 1. Core and Balance Model of Family Leisure Functioning

Family leisure can be observed through the Core and Balance Model of Family Leisure Functioning (Figure 1; Agate et al., 2009, p. 208). This model is based on the family systems theory (Minuchin, 1974), as it finds a balance between stability and change (Iso-Ahola, 1984). The idea of stability and change could first be seen in Olson's Circumplex Model of Marital and Family Systems (1993) in terms of *core* and *balance* leisure. Olson's model "suggests that there are two general categories or patterns of family leisure (core and balance) that families use to meet needs of stability and change" (Zabriskie & McCormick, 2001, p. 283). From Olson's model, the Core and Balance Model emerged.

Zabriskie and McCormick (2001) described core leisure as activities that are mostly inexpensive, home-based, often occurring daily, and usually requiring little planning. These activities demonstrate the concept of "cohesion" from Olson's Circumplex Model (1993). In contrast, Zabriskie and McCormick describe balance leisure as occurring outside the home, less frequently than core leisure, and often requiring more "time, effort, and money" (2001, p. 283). In general, balance leisure is a measure of adaptability with activities representing a family's response to change as the family participates in leisure activities outside of the home (Agate, 2009). Categorizing family leisure in this way allows the researcher to view leisure from multiple perspectives, and to group activities accordingly.

Children with Autism

The diagnosis rate of autism is at an all-time high of 1 in 68 (Centers for Disease Control [CDC], 2013). Having a child diagnosed with autism can often be an unexpected change that can be met with parent denial as parents reorganize the thoughts and goals they once had for their child (Rogers, 2007). Parents of children with autism tend to experience higher levels of stress due to the sometimes extensive diagnostic timeline (Sansosti, Lavik, & Sansosti, 2012), the lack of respite care (Kenny & Corkin, 2011; McCann, Bull, & Winzenberg, 2012), and difficulty of balancing employment with parenting a child with special needs (Lassetter et al., 2007; Sharpe & Baker, 2007). Some parents even leave their jobs in order to better care for their child's need (Meadan, Halle, & Ebata, 2010). Although the previously mentioned stresses are considered challenges, there are also positive rewards associated with having a child with autism (Meadan, et al., 2010), too, although the literature is not extensive.

The Current Study

Due to the dearth of research on FQOL for children with autism (Mactavish & Schleien, 2004), this study aimed to 1) describe the FQOL of children with autism, 2) find connections between FQOL and other areas of child development for children with autism, and 3) compare FQOL for children with autism to the FQOL of typically developing children. Only the first aim is covered in this particular manuscript.

Methods

The first part of this study was carried out through a retrospective chart review (RCR) at Nationwide Children's Hospital's Child Development Center (NCH-CDC). This study benefitted from a collaboration with NCH-CDC because it is a part of the Autism Treatment Network (ATN) offering interdisciplinary assessments that gather vast amounts of data (e.g., demographics, physical, emotional, social, and school functioning) in order to provide the most accurate diagnosis. NCH-CDC is the only ATN hospital within 2 hours of Columbus, and for that reason, it attracts and treats many diverse families (e.g., socioeconomic status, race, and family structure).

Although the second part of this study was not included in this specific paper, it is important to understand how both parts contributed to the overall goal of better understanding and measuring FQOL for children with autism. The second part of this study included collecting data on a comparison group of families with typically developing children, relating to the third aim of the study. Data was collected from one parent (of typically developing children) from each family before the RCR began, and eventually complemented the existing data from the RCR. Likewise, data collected on families of typically developing children addressed demographic information, family leisure, as well as physical, emotional, and social functioning.

Sample for Aim 1

Aim 1 was completed using data from NCH-CDC which is "an Autism Treatment Network [ATN] site—an elite designation in the field of autism treatment and research" (Nationwide Children's, 2015, para. 3). The ATN was founded by Autism Speaks and was intended to be "a collaboration of 14 specialty centers dedicated to providing families with state of the art, multidisciplinary healthcare for children and teens affected by autism. The ATN was established to provide a place for families to go for high quality, coordinated medical care for children and adolescents with autism and associated conditions" (Autism Speaks, 2015, para. 1). All participants were required to have an autism diagnosis in order to be eligible for this study.

The sample (n = 73) consisted of parents of children with autism between the ages of 2 and 7 (Table 1). The minimum age was chosen because NCH-CDC assesses children starting at the age of 2. In addition, with the average age at diagnosis being 4 years old, an age range of 2-7 also catches any children within 2-3 years of that age. Lastly, by making the maximum age 7 years old, the study included students who were referred to testing after entering kindergarten. Because the average age of diagnosis is older for children of a lower socioeconomic status (Mandell, Novak, & Zubritsky, 2005), including children older than 4 is crucial to recruiting a diverse sample.

Instruments

Regarding Aims 1, 2, and 3, there were many instruments utilized; however, for aim 1, only the Family Leisure Activity Profile (FLAP; Zabriskie & McCormick, 2001) was utilized. This measure was used for both families of children with autism and families of typically developing children. It included 16 items revolving around the general types of leisure activities in which the family was like to participate (Zabriskie & McCormick, 2001). "The FLAP measures involvement in family leisure activity patterns based on the Core and Balance Model of

Family Leisure Functioning" (Zabriskie & McCormick, 2001, p. 285). Of the 16 items, half are related to core family leisure and half are related to balance family leisure patterns (Dodd, 2007, p. 269).

	Autism Sample	
	N / M	% / SD
Gender		
Male	65	89
Female	8	11
Race		
White	52	71.2
Black	4	5.5
Asian	4	5.5
Black/White	7	9.6
Other	6	8.2
Income		
$0-$49,999	38	52.1
$50,000-$99,999	17	23.3
$100,00+	10	13.7
Did Not Answer	8	10.9
Age		
	3.22	1.35

Table 1. Demographics: Child Gender, Race, and Income

In addition to frequency, each of the 16 items of the FLAP also asked the participant about his or her satisfaction with this aspect of his or her life. These 16 follow-up questions make up the Family Leisure Satisfaction Scale (FLSS), which "measures satisfaction with family leisure involvement based on the Core and Balance Model" (Agate et al., 2009). Parents were

given the opportunity to rank each aspect of family leisure on a 5 point Likert-type scale with responses ranging from Very Dissatisfied (*1*) to Very Satisfied (*5*).

Additionally, at the end of the 16-item questionnaire, participants were asked 5 questions about their overall satisfaction with family life (SWFL; Zabriskie, 2000). The SWFL scale offered general statements such as, "In most ways my family life is close to ideal," and asked the participant to indicate his or her feelings about the statement based on a 7-point Likert-style scale. The scale ranged from Strongly Disagree (*1*) to Strongly Agree (*7*); however, the SWFL was converted to a 0 to 6 scale for analyses. The SWFL Scale has demonstrated internal consistency in previous studies ($\alpha = .93$; Zabriskie, 2000), and the internal consistency for both samples together in the present study were acceptable ($\alpha = .894$).

Results

Frequency of Family Leisure. Much variation exists in the amount of time the families of children with autism spent in each leisure category (Table 2); however, individually, a number of categories stand out. the most common activities in which families participated were home-based activities, such as watching television, listening to music, reading, or singing. Closely following were family dinners and outdoor activities such as stargazing, gardening, yard work, or going on walks. Families participated in each of these categories, on average, somewhere between weekly (*3*) and daily (*4*).

Investigating the data from the perspective of core versus balance leisure revealed that families participate in more core (home-based) family leisure ($M = 2.59$, $SD = .57$) than balance (community-based) family leisure ($M = 1.08$, $SD = .50$). Comparing the two averages, using a paired samples t-test, revealed that the average time spent in core leisure for families of children with autism was significantly greater than the average time spent in balance leisure ($t(72) =$

21.34, $p < .01$). Overall, core leisure occurred more frequently than balance leisure: however, much variation was found within the frequency of specific items.

	Autism Sample $n = 73$	
	M	SD
Average Overall Frequency	1.84	0.45
Average Core Frequency	2.59	0.57
Dinners	3.51	0.97
Home-Based Activities	3.72	0.80
Indoor Games	2.44	1.39
Crafts and Hobbies	2.45	1.31
Outdoor Activities	3.16	0.94
Outdoor Games	2.63	1.23
Other Family Members	1.10	1.22
Religious/Spiritual Activities	1.32	1.38
Average Balance Frequency	1.08	0.50
Community-Based Social Activities	2.44	0.87
Spectator Activities	1.12	1.43
Sporting Activities	1.09	1.03
Special Events	1.45	0.75
Outdoor Activities	0.94	1.12
Water-based Activities	0.44	0.88
Outdoor Adventure	0.29	0.66
Tourism	0.84	0.69

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

Table 2. Average Frequency of Family Leisure

Family Leisure Satisfaction Scale (FLSS). In terms of satisfaction with specific items and categories of activities on the scale, participants rated their own satisfaction with their participation (Table 3) in family leisure. The only item for which the average satisfaction fell between 3 (*satisfied*) and 4 (*very satisfied*) pertained to home-based activities, such as watching television or listening to music. Between 2 (*neutral*) and 3 (*satisfied*) were outdoor activities,

dinners at home, special events, such as the zoo or a festival, crafts or hobbies, social activities, outdoor adventure, and outdoor games. In terms of parent satisfaction, these activities were in the top 8 out of 16.

	Autism Sample n = 51-73	
	M	SD
Average Overall Leisure	2.63	0.72
Average Core Frequency	2.55	0.83
Dinners	2.86	1.12
Home-Based Activities	3.11	0.99
Indoor Games	2.55	1.06
Crafts and Hobbies	2.75	1.00
Outdoor Activities (yard work/walking)	2.93	1.00
Outdoor Games	2.57	1.12
Other Family Members	2.49	1.06
Religious/Spiritual Activities	2.50	1.14
Average Balance Frequency	2.73	0.78
Community-Based Social Activities	2.65	1.01
Spectator Activities	2.25	1.09
Sporting Activities	2.49	1.06
Special Events	2.82	0.95
Outdoor Activities (camping/hiking)	2.53	1.18
Water-based Activities	2.56	1.09
Outdoor Adventure	2.59	1.13
Tourism	2.53	1.19

Table 3. Family Leisure Satisfaction (FLSS)

In addition, comparing core and balance leisure in terms of the Family Life Satisfaction Scale (FLSS) revealed that the average satisfaction for balance leisure (M = 2.73, SD = .785) was not significantly different than the average satisfaction found from core leisure (M = 2.55, SD .83) ($t(50)$=1.77, p = .083).

Satisfaction with Family Life (SWFL). Again, the SWFL scale was comprised of 5 questions regarding the participant's overall satisfaction with family life, requiring respondents

to rate each question from 0 (*not satisfied*) to 6 (*very satisfied*). The average response on the SWFL was between 4 (*slightly agree*) and 5 (*agree*) ($M = 4.39$, $SD = 1.25$). Although the standard deviation indicated some variance regarding participants' responses, overall, the participants tended to agree that they were satisfied with their family life.

Leisure Frequency and Family Leisure Satisfaction Scale (FLSS). Within the FLAP, some notable correlations existed. In many instances, the frequency of the activity was significantly correlated with the parent's satisfaction with his or her own participation in the activity (Table 4); for example, for 6 of the 8 home-based activities ("core" activities), frequency was positively associated with the participant's satisfaction with his or her own participation. The parent's satisfaction with his or her participation in family leisure was also positively related to six of the eight categories of balance (community-based) leisure, as well.

Leisure frequency and Satisfaction with Family Life Scale (SWFL). A number of significant positive correlations existed between the frequency of family leisure and the parent's SWFL score (Table 5). Overall, the average frequency of the 5 items on the FLAP correlated significantly with the participant's average score on the SWFL questions: dinners together at home; home-based activities, such as watching television; indoor games; crafts and hobbies; and attending other family members' events. In addition, SWFL was also positively correlated with the average frequency across all FLAP items and average core leisure. Similar to the FLSS, a greater frequency of family leisure was associated with higher parent satisfaction on the SWFL scale.

	Autism Sample n = 51-73
	r
Average Overall Satisfaction	0.33*
Average Core Frequency	0.23
Dinners	0.19
Home-Based Activities	0.09
Indoor Games	0.50**
Crafts and Hobbies	0.31**
Outdoor Activities (yard work/walk)	0.31**
Outdoor Games	0.48**
Other Family Members	0.44**
Religious/Spiritual Activities	0.30*
Average Balance Frequency	0.35**
Community-Based Social Activities	0.23*
Spectator Activities	0.31*
Sporting Activities	0.49**
Special Events	0.20
Outdoor Activities (camping/hiking)	0.40**
Water-based Activities	0.29*
Outdoor Adventure	0.08
Tourism	0.41**

*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

Table 4. Associations between Frequency of Family Leisure and FLSS

Potential confounding variables. Correlations between income and family leisure (i.e. frequency, child participation, and satisfaction) were evident. Annual income was positively associated with frequency of family leisure for overall average family leisure; average balance leisure; and specific balance leisure items, such as community-based social activities, special events, and tourism. This is reflective of previous research (Zabriskie & McCormick, 2003), in that, balance (community-based) leisure often has a financial cost associated with it (e.g., eating at restaurants, shopping, or visiting museums), and could, therefore, be influenced by a family's ability to fund such activities. When investigating child age as it related to family leisure, positive significant associations were found between age and satisfaction with attendance at

religious events and special events, indicating that parents of older children had significantly more satisfaction when it came to their participation in those activities.

	Autism Sample $n = 73$
	r
Average Overall Satisfaction	0.33**
Average Core Frequency	0.33**
Dinners	0.28*
Home-Based Activities	0.24*
Indoor Games	0.25*
Crafts and Hobbies	0.27*
Outdoor Activities (yard work/walk)	0.19
Outdoor Games	0.14
Other Family Members	0.27*
Religious/Spiritual Activities	0.04
Average Balance Frequency	0.21
Community-Based Social Activities	0.09
Spectator Activities	0.02
Sporting Activities	0.22
Special Events	0.13
Outdoor Activities (camping/hiking)	0.12
Water-based Activities	0.18
Outdoor Adventure	0.11
Tourism	0.11

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

Table 5. Associations between Frequency of Family Leisure and SWFL

Discussion

Frequency and satisfaction were important to investigate separately and together. Separately, the two variables offered information about specific aspects of a family's life, while together, offered insight regarding the family's goals and priorities. Without knowing a parent's satisfaction with the frequency of any item on the FLAP, it would have been difficult to know how a clinician might be of help to that family. Setting a goal for increased frequency in a

specific aspect of family leisure might only be reasonable if the family was dissatisfied with their frequency of that activity. For a family that is satisfied with "weekly" or "monthly" frequency of an item on the FLAP, a clinician may not want to simply aim to increase their frequency. Instead, these results could begin a conversation with the family. The former example may lead to clinician questions such as, "Why are you satisfied with weekly dinners together?" or "If not by increasing the frequency, how could your satisfaction be improved in regard to this item?"

Although the results of investigating frequency and satisfaction do not lead to a clear equation for improving the FQOL for families of children with autism, together, they offer a clinician the opportunity to look for areas of dissatisfaction, and then assess by using the family's frequency score as to why their satisfaction may be low. In addition, the clinician can also look for areas of high satisfaction for further information about how the family views the frequency of family leisure for each item on the FLAP. Because in this study, frequency and satisfaction were significantly correlated in many instances, increasing a family's frequency of participation in aspects of family leisure would be a logical starting place for clinicians who hope to increase a family's FQOL.

Limitations. One limitation is that this study is correlational, and, therefore, causality cannot be determined; however, even though it is not possible to know what exactly caused a family to have a higher or lower FQOL through this study, the data collected will have the potential to make notable contributions to the field. In addition, this study addressed overall FQOL, but only from the perspective of one family member. Ideally, all members of the family would participate in the study in order to fully implement a systems perspective, but in this case, it was not possible.

Strengths. Currently, no measure of family quality of life (FQOL) is being used by any of the Autism Treatment Network hospitals. As stated previously, "The family is perhaps the most important social context within which disability occurs" (Hu et al., 2011, p. 1108). Using family leisure (assessed by the FLAP) as a measure of FQOL will help to paint a picture of the family of a child with autism.

Conclusion. Overall, family leisure is an important feature of family life for families with typically developing children (e.g., Agate et al., 2010). Participating in family leisure increases the amount of time a family spends together, and it has been found to improve overall family functioning (Zabriskie & McCormick, 2001). This study expanded the current literature to include families of children with autism, and will help researchers, community organizations, businesses, and schools better understand the needs of families of children with autism. Looking at FQOL as it pertains to autism will be groundbreaking and will propel the field into further study of this critical social context. Beginning a dialogue is the first step in improving their FQOL, bringing awareness to FQOL for children with autism.

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